

2023: A Year of Firsts

A report on the activities and achievements
of the Juvenile Arthritis Foundation Australia in 2023



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From the Chair

The year 2023 was a year of 'firsts' in the history of juvenile arthritis and related childhood rheumatic diseases in Australia, and in the evolution of the Juvenile Arthritis Foundation Australia (JAFA) and I am proud to present this, JAFA's third Annual Report to you.

The achievements of 2023 are the manifestation of work over the past two to three years. Each is of high value in its own right and, together, establish a solid foundation which will enable JAFA to move to the next level in its quest for equity for those it represents.

They were:

- Establishing the Australian Juvenile Arthritis Registry (AJAR)
- Australia's first Juvenile Arthritis Week (JAW)
- The results of JAFA's national IMPACT Study
- The first stand-alone federal budget allocation for juvenile arthritis

These achievements do not happen without combined effort and unity of purpose. JAFA thanks the families who are so heavily impacted by these diseases for their support and for using their voices to help make these 'firsts' a reality. The Board is also deeply indebted to its donors, volunteers, pro bono advisors, Medical and Scientific Panel, the professional paediatric rheumatology community, and its staff, without all of whom the advances detailed in this report could not have been achieved.

We also thank the various Health Ministers, their Ministerial and Departmental staff, and the many Members of Parliaments at federal, state and territory levels who are listening and responding to JAFA's advocacy. We look forward to this heightened political awareness translating into tangible gains in access to paediatric rheumatology services in the coming year - especially for families in rural and regional areas.

Also in 2023, the Board regretfully farewellled Ms Emily Sheridan as she stepped down from her directorship and warmly welcomed Ms Arti Brown, and her expertise in governance and risk, as JAFA's newest Director.

Most notably, we are excited and grateful for the opportunity to reduce lifelong pain and disability through the Australian Government's 2023-24 budget allocation to JAFA to undertake a national program: "*Juvenile Arthritis: Early Diagnosis-Early Intervention Change Children's Lives*" due to commence in early 2024.



Andrew Harrison

Chair, Juvenile Arthritis Foundation Australia

February, 2024.



Highlights of 2023

JAFAs 2022 Annual Report: Building Capacity detailed a year dedicated to developing, strengthening and streamlining JAFAs internal infrastructure and capabilities to meet the challenges of the rapidly changing social and economic environment. A large component of future-fitting JAFAs for success and sustainability was the careful development of our Strategic Priorities for 2023-25.

In this, JAFAs third Annual Report: 2023 A Year of Firsts, we celebrate the historic advances that have been realised in the past year while fully acknowledging the magnitude of the task ahead as we strive to position JAFAs to achieve a truly level playing field for children and young people with juvenile idiopathic arthritis (JIA) and other childhood rheumatic diseases (CRDs). Notwithstanding these challenges, we are simultaneously proud and humbled by the progress that has been made in 2023. We attribute this to the influence of JAFAs friends and allies and the generosity of its donors, the commitment of its volunteers, the expertise of its pro bono advisors, the dedication of its staff, the support of the ever-expanding JAFAs community, and the increasing willingness of our politicians of all persuasions to listen and heed the call for a much-needed fair go for those affected by JIA and CRDs.

The key 'firsts' of 2023 centred on:

The establishment of the **Australian Juvenile Arthritis Registry (AJAR)** for 0-24 year olds with JIA and related CRDs which was launched in Australian Parliament House in March 2023 by the Assistant Minister for Health, the Hon Ged Kearney at an event co-hosted by Dr Mike Freeland on behalf of the Parliamentary Friends of Child and Adolescent Health and Mental Health

Holding **Juvenile Arthritis Week March 18-24**, the first national awareness-raising campaign for JIA and CRDs - to be continued in future years

The release of the results of **JAFAs IMPACT Study**, the first detailed national survey of the mental, physical, social, and financial costs of JIA and CRDs in 0-25 year olds in Australia

The allocation of funding to JAFAs from the 2023-24 federal budget to undertake a national health professional awareness, early diagnosis program for JIA - the first stand-alone federal allocation for JIA - which will commence in early 2024 and will be titled *Juvenile Arthritis: Early Diagnosis-Early Intervention Change Children's Lives*.

Other firsts for 2023 include the establishment of a paediatric rheumatology service in Canberra, the release of JAFAs first comprehensive education and information booklet, My JIA, and the establishment of new relationships, for example with Juvenile Arthritis Research in the UK and with Research Australia. Also during 2023, JAFAs position as the 'go to' organisation for JIA and CRDs strengthened considerably with governments and health agencies increasingly turning to JAFAs for information and engagement.

About Juvenile Arthritis

Childhood rheumatic diseases (CRDs) are a group of painful, incurable, inflammatory, autoimmune conditions affecting the joints, eyes and, in some cases, the skin, muscles and internal organs. Juvenile idiopathic arthritis (JIA) accounts for approximately 80% of all CRDs with the remaining 20% made up of less common conditions such as systemic lupus erythematosus, chronic relapsing multifocal osteomyelitis and juvenile dermatomyositis.

JIA affects an estimated 6,000 to 10,000 children aged 0-16 years and up to 30,000 people aged 0-24 years making it one of the most common chronic diseases affecting young Australians. Awareness of JIA among health professionals is so low that some children already have permanent joint damage and loss of vision at the time of diagnosis. Eighty five percent of children experience regular ongoing pain and many suffer a high burden of permanent disability, lost educational opportunity, social marginalisation, and mental ill health.

The treatment of JIA and CRDs is highly complex and involves the use of powerful immune-suppressants, steroids and anti-inflammatory medications, all of which can have serious short and long-term side effects. Many children also require frequent joint aspirations and /or steroid injections into affected joints under general anaesthetic. Many suffer unpredictable acute ‘flares’ of their disease. Consequently, access to specialist multi-disciplinary paediatric rheumatology teams for clinical care and monitoring, self-care education and behavioural and psychosocial support, are essential for all children and young people with JIA and CRDs.

How does it feel?

PAIN

Daily, often severe
 Many joints affected: ankles, knees, elbows, wrists, neck, jaw, fingers, toes
 Eye discomfort
 Disturbed/not enough sleep
 Lonely, depressing
 Prevents play and learning

DISABILITY

Joint damage and deformities
 Loss of vision
 Can damage internal organs
 Reduces normal function: sitting, standing, walking, writing
 Prevents normal childhood: play, sport, family activities, socialising



CONSTANT BATTLE

Unpredictable flares
 eg: fine at breakfast - can't walk by lunch time
 Finding the right medication/s
 Time out and travel for appointments
 Additional impact on family budget
 Social exclusion and stigma
 Mental and emotional toll of pain, medical interventions and social isolation

NO CURE

No cure or prevention
 Treatment aims to reduce pain, maximise mobility and prevent disability
 Involves steroids, immune suppressants, and anti-inflammatories
 Significant serious side-effects.
 Constant medical interventions
 Unpleasant tests and treatments
 eg: injections, infusions, general anaesthetics



Establishing the Evidence Base

The almost complete absence of primary data about JIA and related CRDs was a major factor in the decision to establish Jafa. Jafa remains committed to addressing these deficits and growing the evidence base through its long-term ambition to become a major influencer and funder of Australian research into these diseases. As Jafa enters its fifth year, we are delighted to report on two major 'firsts' in establishing this much needed evidence base.



THE AUSTRALIAN JUVENILE ARTHRITIS REGISTRY

The launch of the Australian Juvenile Arthritis Registry (AJAR), a national minimum dataset registry for 0-24 year olds with arthritis and other rheumatic diseases, on March 21, 2023 by Assistant Health Minister, The Hon Ged Kearney, marked a major milestone in establishing a lasting mechanism for building the evidence base for JIA and CRDs.

Disease specific registries provide data on prevalence; gender and geographic distribution; incidence; main forms of treatment; and track changes in disease and treatment patterns over time. They also form a critical gateway and foundation for future research. Despite being one of the commonest chronic childhood diseases, until now, there has been no national registry for JIA and other CRDs. Over the past few years, Jafa has worked hard to address this deficiency and, to this end, initiated a three way partnership between Jafa, the Australian Paediatric Rheumatology Group, and the A3BC biobank to establish and run the registry.

The launch of AJAR in Parliament House Canberra in March 2023 was a wonderful event co-hosted by Jafa and Dr Mike Freeland, Member for Macarthur, acting on behalf of the Parliamentary Friends of Child and Adolescent Health and Mental Health. Forming part of Jafa's first Juvenile Arthritis Week, the Jafa Board and guests: families, friends, MPs, and Departmental staff, met and mingled to celebrate the launch of AJAR and thank the Condon family who had undertaken a year-long swimathon to raise funds for AJAR.

Jafa thanks Assistant Health Minister Ged Kearney for her generosity in launching AJAR and Dr Freeland for his continuing support. We also feel privileged to have so many children and young people with JIA and CRDs participate in these events and greatly enjoy witnessing how much pleasure they gain from meeting their counterparts and sharing experiences.

THE IMPACT STUDY

The IMPACT Study: Investigating the Mental, Physical And social CosTs of juvenile idiopathic arthritis and childhood rheumatic diseases represents the first comprehensive investigation of the personal and financial costs of JIA and CRDs in Australia. It was commissioned by JAJFA and undertaken in 2023 by researchers from The University of Sydney via a national online survey of 0-25 year olds.

Headline results indicate that children and young people with JIA and CRDs:

- Take 11 to 14 months to get diagnosed
- Suffer a high burden of medication side effects
- Average 25 to 26 visits per year respectively to a range of health professionals
- (Students) miss an average of 12% to 15% of school days respectively.
- Incur higher government costs than comparable chronic diseases.
- Have poor quality of life



Launched by the NSW Health Health Minister, the Hon Ryan Park on November 28, 2023 at a memorable event in NSW Parliament House co-hosted by JAJFA and Dr Joe McGirr, Member of Wagga Wagga, JAJFA's IMPACT Study represents another landmark in the history of JIA and CRDs in Australia. The results provide a sound evidence base for future health policy, planning and decision making, a valuable stepping stone for further research, and another advance towards JAJFA's goal of generating evidence to raise awareness of and motivate action to address the needs of children and young people with these diseases.



JAJFA is grateful to Minister Park and Dr McGirr for their interest and support and sincerely thanks, Adrian and Charlotte MacKenzie and Five V Capital for their generous donation which made the IMPACT Study possible.



Growing Awareness

Political awareness is an essential pre-cursor to policy change and community awareness boosts political awareness. Prior to Jafa's establishment, political and community awareness of JIA and related CRDs in Australia was virtually non-existent. While much more remains to be done, significant advances were made in 2023.

FIRST STAND-ALONE FEDERAL BUDGET ALLOCATION



In May 2023, in response to Jafa's pre-budget submission, the Australian Government acknowledged the seriousness and urgency of reducing late diagnosis of JIA by providing the first stand-alone federal budget funding for JIA to Jafa for a much-needed national health professional awareness - early diagnosis campaign. Jafa is grateful to the Australian Government for this funding allocation which addresses Recommendation 7 of the 2022 Parliamentary Inquiry into Childhood Rheumatic Diseases and is the 'jewel in the crown' of government action resulting from Jafa's political advocacy.

The program has been titled Early Diagnosis-Early Intervention Change Children's Lives. It is set to commence in early 2024 and will primarily target general practitioners.

FIRST AUSTRALIAN JUVENILE ARTHRITIS WEEK

Building on the momentum generated in 2022, Jafa initiated and held Australia's first Juvenile Arthritis Week (JAW) March 18-24, 2023 to raise national awareness of JIA and related CRDs and recognise the bravery of the many children and young people across Australia who must struggle constantly to do ordinary things that their healthy counterparts are able to take for granted.

JAW 2023 was themed on the five core elements of inequality associated with JIA and related CRDs ie: access to care, social, geographic, educational and financial inequality and was predicated on a structured national social media campaign to take the 'in' out of inequality. Highlights included:

- *Family get togethers* in Sydney, Brisbane and Melbourne with the Brisbane and Melbourne events being held in collaboration with Zoe's Angel's and MSK Kids respectively. These fun get togethers were also attended by staff from local paediatric rheumatology teams and enabled several families to meet others dealing with the same issues for the first time
- *An event in Australian Parliament House Canberra* during which the Jafa Board, families and friends met and mixed with federal members of parliament and senior Health Department staff
- *Jafa's 9th Online Symposium* which featured the new generation of Australian paediatric rheumatologists who shared their ideas, interests and aspiration on the Future of Paediatric Rheumatology in Australia.

Jafa is grateful to Sydney's Wests Tigers National Rugby League Club which helped spread the JAW messages via their own social media channels, as did several federal government health department sections and agencies. We are also grateful to the Australian Rheumatology Association, the Australian Paediatric Rheumatology Group and other industry organisations that also took up the challenge. And we are especially grateful to the federal and state politicians who displayed JAW posters in their offices.

Plans for JAW 2024 are already underway and the list of participating organisations is growing.



STATE BASED POLITICAL CAMPAIGNS

JAJA's state-based political campaigns have become a staple tool in its armament for raising political awareness of the plight of children and young people with JIA and CRDs, and the need for public investment to bring services up to an equitable level with comparable chronic childhood conditions. In addition to meeting with federal Health Minister Mark Butler and several state Health Ministers and/or their Ministerial and Departmental staff, in 2023 political advocacy concentrated primarily on two states and one territory: continuing the NSW Campaign, launching a new campaign in Tasmania and conducting an advocacy and media campaign in the ACT.

New South Wales (NSW)



Following the March 2023 state election, JAJA continued to promote its pre-election proposal to the incoming NSW Government through a formal proposal, seeking the allocation of \$1.75 million per year to redress the serious shortfall in NSW paediatric rheumatology services and provide more equitable access to best practice care for affected children and young people, comparable to that which is available for other similarly serious childhood diseases. As a result, the new NSW Minister for Health, the Hon Ryan Park, met with JAJA representatives in June 2023 to discuss the proposal and has expressed a keen interest in addressing the issues raised. As 2023 closed, we understand that the Ministry of Health is working towards solutions and we are hopeful that 2024 will bring some relief to both affected families and the over-worked NSW Paediatric Rheumatology team.

Tasmania



Tasmania has no specialist paediatric rheumatology service forcing affected families to undertake costly and stressful travel to Melbourne for their child's treatment - or try to access the limited service in Hobart generously provided by a local adult rheumatologist. Consequently, in August 2023, in consultation with affected families and in collaboration with Arthritis Tasmania, JAJA submitted a formal proposal requesting the Tasmanian Government to establish a statewide paediatric rheumatology service for the modest cost of around \$500,000 per year. On meeting with the Tasmanian Health Minister in October 2023, JAJA and Arthritis Tasmania were advised the proposal will be considered alongside planned changes to other paediatric services due in early 2024. In support of the proposal, JAJA is following up with a media campaign due to go live in January 2024.

Australian Capital Territory (ACT)



Many ACT families and young people with JIA and related CRDs have traditionally travelled to Sydney in order to access treatment. This was exacerbated two years ago by the retirement of the ACT adult rheumatologist who ran a limited service for children. Since then, there have been various attempts to rectify the situation and in 2023 JAJA added its voice, liaising closely with local families about their needs, making representations to the ACT Health Minister, collaborating with ACT ABC TV on a media campaign advocating for appropriate services. We are delighted to report that as of December 2023, the ACT now provides a twice monthly local paediatric rheumatology service. While more is needed, this new service is a welcome advance.

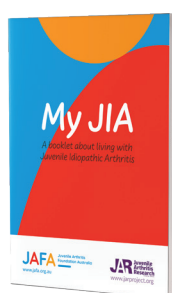
In 2024 JAJA will vigorously pursue the two campaigns in progress in NSW and Tasmania and plans to mount a pre-election campaign targeting both major political parties in Queensland in advance of that state's forthcoming election on October 26, 2024.

Supporting the Jafa Community

Jafa offers a community of interest to parents, carers, children, young people, and close relatives affected by JIA and CRDs. Jafa supports its growing community through peer interaction, providing credible and current information, consultation to grow self-awareness and determination, and a unifying voice to express common needs and concerns.

MY JIA HANDBOOK

In another first for 2023, Jafa is proud and delighted to have presented this much-needed, succinct but highly informative booklet about JIA as our World Arthritis Day gift to all children, young people and families in Australia who are living with it. My JIA was adapted and reproduced for Australia by Jafa with the kind permission of its original author and owner, the UK-based Juvenile Arthritis Research (JAR). It is a comprehensive, user-friendly, and highly credible explanation of:



- The main types of JIA
- The main medications used in Australia, and non-medical therapies
- Why and how paediatric rheumatologists monitor JIA
- What parents or individuals need to do in the 'home' management of JIA.

My JIA includes tips for managing school life, sport and more and is suitable for children from mid to late primary school to older children and young adults, parents, grandparents, teachers, child minders and others - and could easily be read to younger children: www.jafa.org.au/my-jia-booklet/

Jafa thanks JAR for its generosity in allowing us to share My JIA. We also thank the Australian paediatric rheumatology professionals (nurses, occupational therapists, physiotherapists and doctors) and parents, who carefully reviewed, revised and helped Jafa adapt My JIA to be optimally relevant to Australia.

ONLINE SYMPOSIUM SERIES FOR PARENTS, OLDER CHILDREN AND YOUNG ADULTS



Jafa assists parents, carers, older children and young adults to understand JIA and CRDs, their management, how to navigate the health system and understand emerging research and treatment through accurate and current information. Established shortly after Jafa's inception, an important mechanism for this is Jafa's online symposia series which features paediatric rheumatologists, uveitis specialists, nurses and allied health professionals who share their knowledge and expertise on critical issues and advances in treatment and research.

Themes for the 2023 symposia were:

- The Future of Paediatric Rheumatology in Australia, featuring the new generation of Australia's paediatric rheumatologists talking about their views, interests and ambitions.
- New and Emerging Australian Research and Consumer Led Research Priorities

Around 100 people register for each symposium which is also recorded, indexed and placed on the Jafa website thus creating a rich and freely available library of valuable information and education resources: www.jafa.org.au/jafa-symposia-series

KIDSCONNECT

Now in its third year, KidsConnect is an innovative, secure, purpose-built online platform where 7-17 year olds with JIA or related CRDs can meet and engage with counterparts in a safe digital space via age-appropriate chat and game resources (Minecraft and Discord) unhampered by distance or physical limitations. Originally funded by a St George Community grant in 2021, brainchild of Jafa supporter and digital communications expert, Dr Shilo McClean, and run by Jafa's Digital Lead, Ben Laxton, KidsConnect commenced in early 2022. Since then it has provided a much-enjoyed mechanism for bringing together children and adolescents with arthritis and rheumatic diseases in a friendly and inclusive environment. For more details about KidsConnect and how to register please contact kidsconnect@jafa.org.au.



Jafa Juvenile Arthritis Foundation Australia

KIDSCONNECT

Connecting kids with juvenile arthritis

 Join up for some online fun and games playing Minecraft

 Meet other kids with juvenile arthritis

 Hang out and chat

Safe, secure and moderated platform
Open to kids aged 7-17yrs

Visit www.jafa.org.au/kidsconnect to find out more and sign up for a welcome pack, or scan the QR code

Meet new friends and join in the fun



SUPPORTING PARENTS, OLDER CHILDREN AND YOUNG ADULTS

Jafa links parents, older children and young adults living with JIA and CRDs through its almost 800 families strong private Facebook group, and through ad hoc parent meetings, in-person events, and email support groups. Jafa staff and volunteers enormously enjoy communicating directly with dozens of Jafa constituents each week.



SPEAKING UP - SPEAKING OUT

One of the many ways Jafa supports its constituents is by providing a conduit for the Jafa Community to use its voice to articulate its needs for health care services and support. To this end, Jafa offers tools such as 'Lobbying Packs', letter templates and tips on how to approach local MPs and/or seek local media attention. Jafa also encourages and supports its constituents to respond to relevant public consultations. As a result, over the course of 2022-2023, there has been a noticeable increase in confidence and capacity of families to speak up and speak out about their needs.

SUBMISSIONS AND SUPPORT FOR ADVANCES IN TREATMENT AND CARE

Since its inception Jafa has made a number of submissions in response calls by governments and their agencies for public consultation. In 2023 this included:

Pharmaceutical Benefits Advisory Scheme (PBAC)

In January 2023, Jafa made a submission to the public consultation regarding possible Pharmaceutical Benefits Scheme (PBS) listing of Tofacitinib, the first oral biological medication to be introduced into Australia. Jafa subsequently participated in the advocacy campaign which culminated in the Federal Health Minister, the Hon Mark Butler, announcing the PBS listing of this medication on December 9, 2023.

Jafa has also been active in advocating to the PBAC to consider expanding the current listing of the anti-rheumatic medication, Adalimumab, to include children with uveitis and children with less than five affected joints. This is due to be considered at the March 2024 meeting of the PBAC.

The NSW Special Commission of Inquiry into Healthcare Funding

Jafa responded in October 2023, to the call for public submissions to the above inquiry and was grateful for the opportunity to detail the serious inequalities in NSW funding of services for children and young people with JIA and CRDs – especially those living in rural and regional NSW. The Commission is expected to hand down its report in 2024.

Expanding Reach and Influence

In 2023 Jafa continued to work on enhancing its reach, influence and brand recognition as a means of strengthening its capacity to optimally represent and advocate for children and young people with JIA and CRDs. This has resulted in unprecedented political and community awareness of JIA and CRDs and increasing recognition of and respect for the Jafa brand, and demand for Jafa's input and representation.

NETWORKS

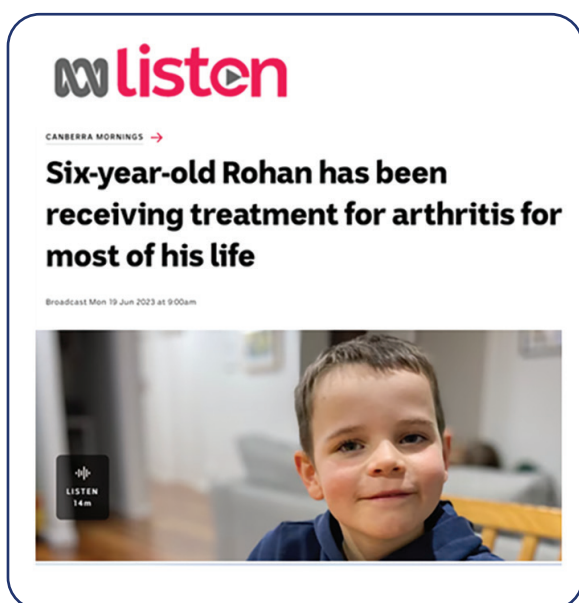
Jafa continues to engage with the Paediatric Global Musculoskeletal Task Force and the European Network for Childhood Arthritis and Autoinflammatory diseases (ENCA) on matters of mutual interest. In 2023, Jafa was delighted to formalise the friendship with its UK counterpart, Juvenile Arthritis Research (JAR) for the purpose of adapting JAR's information booklet, My JIA, for the Australian audience.

Closer to home, 2023 saw Jafa expand its local networks, for example, collaborating with Arthritis Tasmania to propose the establishment of a statewide paediatric rheumatology service to the Tasmanian Government. Additionally, during 2023 Jafa and the Australian Rheumatology Association (ARA) established an excellent working relationship, and Jafa became a member of Research Australia. Jafa values these relationships highly for the rich friendship and wider perspectives they bring to all involved.

A STALL IN THE HALL

The so called 'Trade Hall' is the busy, bustling, unofficial heart of all medical and scientific conferences. It is a heart pumping with life and excitement and is where registrants, speakers, organisers, and representatives of pharmaceutical companies and patient organisations meet and mingle to swap intelligence, exclaim over new research, marvel at advances, and refresh or initiate new collaborations and partnerships. So when the ARA offered Jafa 'a stall in the hall' at its 2023 Annual Conference in Hobart, we accepted with gratitude, and sincerely thank the ARA for the opportunity to be part of this important national event – a pivotal 'first' in expanding Jafa's reach and presence in the professional community.

THE WORD IS OUT



While a continuing and concerted effort is required to raise awareness of JIA and related CRDs to the same level as comparable chronic childhood conditions, 2023 has demonstrated that 'the word' is indeed out. This is expressed in numerous and varied ways. Not least of these are anecdotal reports from the professional paediatric rheumatology community and Jafa families of increased awareness and on-the-ground improvements. Other evidence includes increases in approaches to Jafa for input and collaboration, a measurable expansion in Jafa's mainstream and social media presence, and tangibly increased political goodwill. So, while much remains to be done, it is fair to say that the 'genie is out of the bottle' and political and social awareness of JIA and related CRDs has never been higher.

Strategic Priorities 2023-25

JAFa is strongly committed to strategic planning. To this end, it has clearly articulated its purpose and aspirations from the outset and, in 2023, its direction and efforts were supported by the first year of its new three year plan which is equipping JAFa well to act decisively and effectively into the foreseeable future.

JAFa's direction and activities in 2023 were guided by its new Strategic Priorities for 2023-2025 which were developed in late 2022 and designed to assist and support JAFa to capitalise on past gains, and position itself for future success in:

- Effectively championing and addressing the interests and needs of children and young people with arthritis and related rheumatic diseases.
- Meeting the rapidly emerging challenges of a new and ever-changing political, socio-economic and policy environment.

STRATEGIC PRIORITIES FOR 2023-25

Priority 1:

Juvenile arthritis is diagnosed within 10 weeks and referred to care by paediatric rheumatology teams.

Priority 2:

Affordable best practice treatment, care and support is accessible to all children and young people with arthritis.

Priority 3:

A prioritised and diverse consumer driven research agenda for juvenile arthritis is under way and funded.

Priority 4:

All levels of government and the community are aware of juvenile arthritis and its financial & economic burden

Priority 5:

JAFa is an effective, respected, well-resourced, sustainable organisation effectively serving children and young people with arthritis and related rheumatic diseases and their families

Following a year of testing in 2023, JAFa's Strategic Priorities were found to be more than 'road worthy' and reaped tangible rewards across all five priority areas. Gains were particularly strong in Priority 4 as evidenced by the Federal Government and the Australia-wide response to JAFa's political advocacy, and in Priority 5 which saw JAFa considerably increase and improve its strategic and operational capabilities.

Advances in Priority 3 during 2023 included the establishment of the AJAR database, the IMPACT Study results which included a list of consumer-led research priorities, becoming a member of Research Australia, and increased consumer engagement in academic research and that of government agencies such as the Australian Institute of Health and Welfare. Under Priority 2, JAFa was delighted to have influenced the i) establishment of a paediatric rheumatology outreach service to the ACT, and ii) its role in the approval of a new oral medication for JIA and a reduction in red tape around the prescribing of certain JIA-CRD medications.

And, finally, the significance of the 2023-24 federal budget allocation to JAFa for a national health professional awareness - early diagnosis program for JIA presents a wonderful window of opportunity for beginning to shift Priority 1 from a pipedream towards reality in 2024.

Board of Directors



ANDREW HARRISON, BEC MBA (CHAIR)

Andrew is an experienced company director and corporate adviser. He is non-executive chairman of ASX-listed WiseTech Global Limited and has held executive roles and non-executive directorships with public and private companies. He has served as CFO of Seven Group Limited and Landis & Gyr and has worked internationally as an investment banker and Chartered Accountant. He holds a BEc from the University of Sydney and an MBA from the Wharton School. He is a Chartered Accountant and a member of the Australian Institute of Company Directors. Andrew has a child with arthritis.



ARTI BROWN

Arti has over 20 years of experience in public policy and advocacy, regulatory affairs, governance, risk management and organisational design. Having worked across mining, telecommunications and more recently, finance, Arti currently drives Line 1 Risk Strategy, Governance and Operations as a General Manager at the Commonwealth Bank of Australia. Arti is a graduate of the University of Sydney, and is a member of the Australian Institute of Company Directors and Chief Executive Women. Arti has a daughter with Juvenile Arthritis.



RUTH COLAGIURI AM (FOUNDER)

Ruth is an Honorary Associate Professor of the University of Sydney Menzies Centre for Health Policy-School of Public Health. She has worked in clinical care, health policy and health services research in the NSW hospital system, Health Department and academia and led projects and commissioned work for AusAID, the WHO, the OECD. She is a former V-P of the International Diabetes Federation, Diabetes Australia and served on national and international advisory committees. She has a grandchild with arthritis.



STEPHEN COLAGIURI AO (CO-FOUNDER)

Stephen Colagiuri is Professor of Metabolic Health, Director of the Boden Collaboration of Obesity, Nutrition, Exercise & Eating Disorders, and Solutions Domain Leader at the University of Sydney's Charles Perkins Centre. He is a medical specialist in diabetes and has worked in public and private health systems and universities. He advises the WHO, sits on the Health Minister's National Diabetes Advisory Group and is a V-P of the International Diabetes Federation. Stephen has a granddaughter with arthritis.



TANYA DMITRONOW (DIRECTOR)

Tanya recently returned to Australia with her husband and three children after nearly twenty years in New York and London. She was a partner at a leading New York law firm where she specialised in shareholder litigation, regulatory investigations and corporate governance. Tanya advised some of the largest public companies and board directors in the healthcare, technology and financial-services sectors. She graduated from Bond University and New York University where she was a Fulbright Scholar. Tanya has navigated both the US and Australian health systems with her young child with arthritis.

Staff and advisors



ANGELA MCKAY (CEO)

Angela McKay joined Jafa in late 2020. Angela has over 20 years senior leadership experience spanning the private and not-for-profit sectors and extensive experience in disease-specific non-profits for children having spent 8yrs as COO of the Juvenile Diabetes Research Foundation prior to joining Jafa.



BEN LAXTON (DIGITAL PROJECT LEAD)

Ben Laxton joined Jafa in June 2021, bringing with him a wealth of experience and expertise in digital technology and communication in the private sector, the public health system and health non-profits.

MEDICAL AND SCIENTIFIC ADVISORY PANEL

Jafa is fortunate to have access to continuing advice and guidance on medical and scientific matters from four of Australia's most prominent and highly respected paediatric rheumatology clinicians and researchers, and an ophthalmologist in the field of uveitis:

- Dr Jeffrey Chaitow (Chair), Head, Paediatric Rheumatology, Sydney Children's Hospitals Network
- A/Professor Jane Munro, Paediatric Rheumatologist, Royal Children's Hospital, Melbourne
- Professor Davinder Singh-Grewal, Paediatric Rheumatologist, SCHN
- Dr Ben Whitehead, Director Paediatric Rheumatology, Queensland Children's Hospital
- Dr Sophia Zagora, Ophthalmologist and Uveitis Specialist, The University of Sydney.

SUPPORTERS

Jafa is grateful for the generosity of its donors and for the very valuable pro bono contribution of:

- **Legal and Governance** - Garry Beath, MinterEllison, Sydney
- **Media and Publicity** - Felicity Moffat, Founder and Principal MD Media
- **Health Policy and Strategy** - Associate Professor Christine Giles, Menzies Centre for Health Policy and Economics, The University of Sydney, and Independent Director.
- **Communications** - Lisa McDermott, Director EngageComms
- **Social media and Digital Technology** - Dr Shilo McClean, an expert in her field and mother of a young adult with juvenile onset arthritis.

VOLUNTEERS

Jafa is deeply grateful to the dedicated parent volunteers who have supported it since its inception and, without whose input and conviction that change is possible, Jafa would not have flourished.



Jafa's First Advocacy Champion

In February 2022, Victoria Allen, a former market leading merger and acquisitions lawyer and partner at MinterEllison, stepped down from her role as Jafa's inaugural chair. Fortunately, Victoria has remained actively engaged in her new role as Jafa's first Advocacy Champion and continues to work closely with the Board and CEO to support Jafa's advocacy.

About JAFA

The Juvenile Arthritis Foundation Australia (JAFA) is the primary organisation representing children with juvenile arthritis and related rheumatic diseases and their families in Australia and was named *Emerging Not-for-Profit of the Year* in the 2021 Third Sector Awards.

JAFA is a fully registered national charity with DRG1 status founded in 2019 in response to the urgent need for a national voice dedicated exclusively to representing and addressing the needs of children, adolescents and young people with arthritis and related rheumatic diseases and their families and carers.

JAFA provides direct services to children and adolescents with juvenile arthritis and related rheumatic diseases and their families through support groups, regular online symposia on critical management and research issues, and a secure, digital play space, KidsConnect, to provide peer support and reduce isolation. However, its core focus is on political advocacy to raise awareness among high level policy makers in order to effect systemic and sustainable change to improve the lives of children and young people with these diseases. Implicit in this is connecting the affected community and raising awareness among health professionals and the general community.

VISION



Our vision is a world where kids really don't get arthritis.

MISSION



Our Mission is to stop pain and disability in children with arthritis through:

- Earlier diagnosis, improved treatment, care and support
- Increased professional, community, and political awareness and advocacy
- Building communities of influence to fund vital research and programs

VALUES



JAFA strives to be an innovative, agile, effective and influential force that is:

- Unwavering in its dedication to meeting the needs of children and young people with arthritis, and rheumatic diseases, families and carers
- Open and transparent in all its dealings
- Strategic, and receptive to ideas and opportunities
- Sensitive to and respectful of diversity and differences
- A supportive collaborator

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Jafa has DRG status
and is registered with
the Australian Charities
and Not-for-Profits
Commission (ACNC).



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